Senate Bill No. 683

CHAPTER 444

An act to amend Sections 103850 and 103885 of the Health and Safety Code, relating to public health information, and declaring the urgency thereof, to take effect immediately.

[Approved by Governor October 2, 2001. Filed with Secretary of State October 3, 2001.]

LEGISLATIVE COUNSEL'S DIGEST

SB 683, Ortiz. Public health information: confidentiality.

Existing law relating to public health surveillance provides for the collection of information with respect to birth defects monitoring, and also with respect to determination of the incidence of cancer. Existing law further provides for the confidentiality of this information, except as specified.

The bill would specifically designate the information described above as ''confidential information.'' This bill would recast and revise the confidentiality requirements relating to each of the above subjects, including providing that the confidential information shall not be available for subpoena, or disclosed, discoverable, compelled to be produced, or admissible as evidence in any civil, criminal, administrative, or other proceeding. This bill would provide that individuals to whom the confidential information pertains shall have access to their own information in accordance with the Information Practices Act of 1977.

This bill would declare that it is to take effect immediately as an urgency statute.

The people of the State of California do enact as follows:

SECTION 1. Section 103850 of the Health and Safety Code is amended to read:

103850. (a) All information collected pursuant to this chapter shall be confidential and shall be used solely for the purposes provided in this chapter. For purposes of this chapter, this information shall be referred to as ''confidential information.'' Access to confidential information shall be limited to authorized program staff, and persons with a valid scientific interest, who meet qualifications as determined by the director, who are engaged in demographic, epidemiological or other similar

studies related to health, and who agree, in writing, to maintain confidentiality.

(b) The department shall maintain an accurate record of all persons who are given access to confidential information. The record shall include: the name of the person authorizing access; name, title, address, and organizational affiliation of persons given access; dates of access; and the specific purpose for which information is to be used. The record of access shall be open to public inspection during normal operating hours of the state department.

(c) All research proposed to be conducted by persons other than program staff, using confidential information in the system, shall first be reviewed and approved by the director and the State Committee for the Protection of Human Subjects. Satisfaction of the terms of the director's rules for data access shall be deemed to establish a valid scientific interest for purposes of subdivision (a), entitling the researcher to review records collected pursuant to Section 103830 and to contact case subjects and controls. Before confidential information is disclosed pursuant to this section to any other person, agency, or organization, the requesting entity shall demonstrate to the department that the entity has established the procedures and ability to maintain the confidentiality of the information.

(d) Notwithstanding any other provision of law, any disclosure authorized by this section shall include only the information necessary for the stated purpose of the requested disclosure, and shall be made only upon written agreement that the information will be kept confidential, used for the approved purpose, and not be further disclosed.

(e) The furnishing of confidential information to the department or its authorized representative in accordance with this section shall not expose any person, agency, or entity furnishing the information to liability, and shall not be considered a waiver of any privilege or a violation of a confidential relationship.

(f) Whenever program staff, pursuing program objectives, deems it necessary to contact case subjects and controls, program staff shall submit a protocol describing the research to the director and to the State Committee for the Protection of Human Subjects. Once a protocol is approved by that committee, program staff shall be deemed to have established a bona fide research purpose, and shall be entitled to complete the approved project and contact case subjects and controls without securing any additional approvals or waivers from any entity.

(g) Notwithstanding any other provision of law, no part of the confidential information shall be available for subpoena, nor shall it be disclosed, discoverable, or compelled to be produced in any civil, criminal, administrative, or other proceeding, nor shall this information

be deemed admissible as evidence in any civil, criminal, administrative, or other tribunal or court for any reason. Nothing in this section shall prohibit the publishing by the department of reports and statistical compilations relating to birth defects, stillbirth, or miscarriage that do not in any way identify individual cases or individual sources of information.

(h) Any person who, in violation of a written agreement to maintain confidentiality, discloses any information provided pursuant to this section, or who uses information provided pursuant to this section in a manner other than as approved pursuant to this section may be denied further access to any confidential information maintained by the department. That person shall also be subject to a civil penalty of five hundred dollars ($500). The penalty provided in this section shall not be construed as restricting any remedy, provisional or otherwise, provided by law for the benefit of the department or any person.

(i) Notwithstanding the restrictions in this section, an individual to whom the information pertains shall have access to his or her own information in accordance with Chapter 1 (commencing with Section 1798) of Title 1.8 of the Civil Code.

SEC. 2. Section 103885 of the Health and Safety Code is amended to read:

103885. (a) The director shall establish a statewide system for the collection of information determining the incidence of cancer, using population-based cancer registries modeled after the Cancer Surveillance Program of Orange County. As of the effective date of this section the director shall begin phasing in the statewide cancer reporting system. By July 1, 1988, all county or regional registries shall be implemented or initiated. By July 1, 1990, the statewide cancer reporting system shall be fully operational. Within 60 days of the effective date of this section, the director shall submit an implementation and funding schedule to the Legislature.

(b) The department may designate any demographic parts of the state as regional cancer incidence reporting areas and may establish regional cancer registries, with the responsibility and authority to carry out the intent of this section in designated areas. Designated regional registries shall provide, on a timely basis, cancer incidence data as designated by the state department to the department. The department may contract with an agency, including, but not limited to, a health systems agency, single county health department, multicounty health department grouping, or nonprofit professional association, representing a designated cancer reporting region for the purposes of collecting and collating cancer incidence data.

(c) The director shall designate cancer as a disease required to be reported in the state or any demographic parts of the state in which cancer information is collected under this section. All cancers diagnosed or treated in the reporting area shall thereafter be reported to the representative of the department authorized to compile the cancer data, or any individual, agency, or organization designated to cooperate with that representative.

(d) (1) Any hospital or other facility providing therapy to cancer patients within an area designated as a cancer reporting area shall report each case of cancer to the department or the authorized representative of the department in a format prescribed by the department. If the hospital or other facility fails to report in a format prescribed by the department, the department's authorized representative may access the information from the hospital or the facility and report it in the appropriate format. In these cases, the hospital or other health facility shall reimburse the state department or the authorized representative for its cost to access and report the information.

(2) Any physician and surgeon, dentist, podiatrist, or other health care practitioner diagnosing or providing treatment for cancer patients shall report each cancer case to the department or the authorized representative of the department except for those cases directly referred to a treatment facility or those previously admitted to a treatment facility for diagnosis or treatment of that instance of cancer.

(e) Any hospital or other facility that is required to reimburse the department or its authorized representative for the cost to access and report the information pursuant to subdivision (d) shall provide payment to the department or its authorized representative within 60 days of the date this payment is demanded. In the event any hospital or other facility fails to make the payment to the department or its authorized representative within 60 days of the date the payment is demanded, the department or its authorized representative may, at its discretion, assess a late fee not to exceed $1^1/_2$ percent per month of the outstanding balance. Further, in the event that the department or its authorized representative takes a legal action to recover its costs and any associated fees, and the department or its authorized representative receives a judgment in its favor, the hospital or other facility shall also reimburse the department or its authorized representative for any additional costs it incurred to pursue the legal action. Late fees and payments made to the department by hospitals or other facilities pursuant to this subdivision shall be considered as reimbursements of the additional costs incurred by the department.

(f) All physicians and surgeons, hospitals, outpatient clinics, nursing homes and all other facilities, individuals or agencies providing

diagnostic or treatment services to patients with cancer shall grant to the department or the authorized representative access to all records that would identify cases of cancer or would establish characteristics of the cancer, treatment of the cancer, or medical status of any identified cancer patient. Willful failure to grant access to those records shall be punishable by a fine of up to five hundred dollars ($500) each day access is refused. Any fines collected pursuant to this subdivision shall be deposited in the General Fund.

(g) (1) Except as otherwise provided in this section, all information collected pursuant to this section shall be confidential. For purposes of this section, this information shall be referred to as ‘‘confidential information.’’

(2) The department and any regional cancer registry designated by the department shall use the information to determine the sources of malignant neoplasms and evaluate measures designed to eliminate, alleviate, or ameliorate their effect.

(3) Persons with a valid scientific interest who are engaged in demographic, epidemiological, or other similar studies related to health who meet qualifications as determined by the department, and who agree, in writing, to maintain confidentiality, may be authorized access to confidential information.

(4) The department and any regional cancer registry designated by the department may enter into agreements to furnish confidential information to other states’ cancer registries, federal cancer control agencies, local health officers, or health researchers for the purposes of determining the sources of cancer and evaluating measures designed to eliminate, alleviate, or ameliorate their effect. Before confidential information is disclosed to those agencies, officers, researchers, or out-of-state registries, the requesting entity shall agree in writing to maintain the confidentiality of the information, and in the case of researchers, shall also do both of the following:

(A) Obtain approval of their committee for the protection of human subjects established in accordance with Part 46 (commencing with Section 46.101) of Title 45 of the Code of Federal Regulations.

(B) Provide documentation to the department that demonstrates to the department’s satisfaction that the entity has established the procedures and ability to maintain the confidentiality of the information.

(5) Notwithstanding any other provision of law, any disclosure authorized by this section shall include only the information necessary for the stated purpose of the requested disclosure, used for the approved purpose, and not be further disclosed.

(6) The furnishing of confidential information to the department or its authorized representative in accordance with this section shall not

expose any person, agency, or entity furnishing information to liability, and shall not be considered a waiver of any privilege or a violation of a confidential relationship.

(7) The department shall maintain an accurate record of all persons who are given access to confidential information. The record shall include: the name of the person authorizing access; name, title, address, and organizational affiliation of persons given access; dates of access; and the specific purpose for which information is to be used. The record of access shall be open to public inspection during normal operating hours of the department.

(8) Notwithstanding any other provision of law, no part of the confidential information shall be available for subpoena, nor shall it be disclosed, discoverable, or compelled to be produced in any civil, criminal, administrative, or other proceeding, nor shall this information be deemed admissible as evidence in any civil, criminal, administrative, or other tribunal or court for any reason.

(9) Nothing in this subdivision shall prohibit the publication by the department of reports and statistical compilations that do not in any way identify individual cases or individual sources of information.

(10) Notwithstanding the restrictions in this subdivision, the individual to whom the information pertains shall have access to his or her own information in accordance with Chapter 1 (commencing with Section 1798) of Title 1.8 of the Civil Code.

(h) For the purpose of this section, ''cancer'' means either of the following:

(1) All malignant neoplasms, regardless of the tissue of origin, including malignant lymphoma, Hodgkins disease, and leukemia, but excluding basal cell and squamous cell carcinoma of the skin.

(2) All primary intracranial and central nervous system (CNS) tumors occurring in the following sites, irrespective of histologic type: brain, meninges, spinal cord, caudae equina, cranial nerves and other parts of the CNS, pituitary gland, pineal gland, and craniopharyngeal duct.

(i) Nothing in this section shall preempt the authority of facilities or individuals providing diagnostic or treatment services to patients with cancer to maintain their own facility-based cancer registries.

(j) It is the intent of the Legislature that the department, in establishing a system pursuant to this section, maximize the use of available federal funds.

SEC. 3. This act is an urgency statute necessary for the immediate preservation of the public peace, health, or safety within the meaning of Article IV of the Constitution and shall go into immediate effect. The facts constituting the necessity are:

In order to improve the health and well-being of the citizens of California, their confidential health data maintained by the state for public health surveillance and research purposes only must be protected from misuse and disclosure through subpoena and other court proceedings at the earliest possible time. It is therefore necessary that this act take effect immediately.

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